Mental Retardation Staff ORIENTATION WORKBOOK

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FOREWORD

The Office of Mental Retardation is pleased to present the Orientation Workbook to Community Service Boards and other providers of services and supports to individuals with mental retardation. We are indebted to the original authors of the "Orientation Workbook," Lisa Poe and Glenda Edwards, for their exceptional work on this project. While it was developed to enable providers to meet the staff training requirements under the Mental Retardation (MR) Community Waiver, this Orientation Workbook can be an invaluable tool for training new and experienced staff in any type of MR program. The widely accepted values and current best practices for supporting people with mental retardation and other developmental disabilities are outlined clearly and concisely. Included are practical tips to help staff apply the principles presented. The Orientation Workbook is designed for use by the program supervisor in building the competence and confidence of new employees.

As reflected in the regulations for the MR Community Waiver, all agency staff who provide Medicaid-reimbursed Residential Support, Personal Assistance, Day Support or Prevocational services in Virginia must receive training in providing services and supports to individuals with mental retardation. Those providing Residential Support or Personal Assistance services must use this Workbook and possess basic proficiency as demonstrated on the accompanying competency test. This test must be administered by a program supervisor who attended one of the 1997 statewide Department of Mental Health, Mental Retardation, and Substance Abuse Services training sessions, received instruction on the use of the Orientation Workbook from a supervisor who attended one of the '97 trainings, or has viewed a copy of the "Supervisor Training Videotape." The Orientation Workbook defines and illustrates standards of practice addressed on the competency test. Staff are to read, study, and **discuss the text with their supervisors** prior to completing the test. The program supervisor must review with every employee each section of the Workbook as it relates to their particular agency's goals and services. This training process must be completed within 30 days of the date that the employee begins to provide MR Waiver services. Each employee must pass the test with an overall score of 75% or better in order to continue providing MR Waiver Residential or Personal Assistance services. If the employee does not have a passing score, the supervisor should review the problem areas with the employee until satisfied that the employee comprehends and then retest. It is suggested that agency staff providing Day Support or Prevocational services also use this Workbook, although another, comparable tool may be used instead. Completion of the accompanying competency test is option for these staff.

A valuable companion to the Staff Orientation Workbook is the more comprehensive staff training manual "MR Best Practice Training" (12/97). This may be an additional resource in staff development and may be obtained from the Office of Mental Retardation.

We hope you are pleased with the Orientation Workbook and welcome your comments on its usefulness and content. You will find an evaluation form on page 46. Thank you for completing this form and returning

it to our office with your reactions.

Section I: THE VALUES THAT SUPPORT LIFE IN THE COMMUNITY

Introduction

Providing services and supports to persons with mental retardation in their own homes and communities is still fairly new, and we are continually learning about better ways of helping them to live regular lives. The requirement for schools to provide special education and the first wave of people leaving institutions (deinstitutionalization) did not become realities until the mid-1970s. In Virginia, the first group of institutionalized persons with mental retardation returned to the community in the late 1970s. After spending the majority of their lives in large state training centers or hospitals, many of these people have lived successfully in group homes or apartments and worked productively in the community for years. The MR Waiver has created opportunities to bring people with more challenging disabilities back to the community, where they will enjoy a broader range of options to grow and contribute.

In the twenty-five years or so since deinstitutionalization began in earnest, a great deal has been learned through research and actual experience about the best ways of teaching and supporting persons with mental retardation. In the last two decades, our society has changed significantly in the way we view persons with disabilities. Though our knowledge continues to evolve, we have a much better understanding of *what works* and *what doesn't work* in supporting persons with disabilities in leading active and fulfilled lives in the community.

The intent of this section of the Orientation Workbook is to introduce you to the *values* that should guide you in your work with persons who have mental retardation

The concepts we will review include:

- Normalization
- Dignity of Risk
- Community Presence and Participation
- Nonrestrictive Program Alternatives
- Natural Supports
- Personal Choice
- Respect
- Individual Rights
- Zero Reject

While some of these terms might sound quite complex at first glance, you will see as you read further that they are actually just simple, common sense ideas. Each concept is

defined below, along with discussion of the role you will play as a staff person in applying these principles.

Normalization

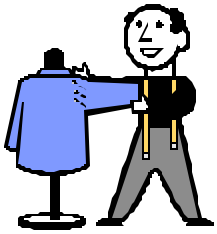
The principle of *normalization* holds that persons with mental retardation should be supported in leading lives which by daily routine, opportunities, expectations, and treatment are as much like other people in their community and of their age as possible. Wolf Wolfensburger, an early advocate for community services for persons with disabilities, developed the term *normalization* in 1980.

Wolfensburger recognized that people with mental retardation are not all alike. They have needs, interests, and abilities that are *more like* those of people without disabilities than different. An individual's life experience is strongly affected by how others see him or her. Adults with mental retardation who are supported in doing regular and valued things that other people their age do in the community in which they live are viewed in a positive manner.

What's Your Role?

Ways in which *you* can implement the concept of *normalization* include:

- Assist the individuals you support in buying attractive, well-fitting and affordable but fashionable clothing which is appropriate for their age and gender.



- Assist people *individually* in going to a neighborhood beauty salon or barber shop for their haircuts. How about a manicure?

- Accompany the persons individually to the bank to cash their paychecks (as opposed to pulling the van up to the drive through and passing five sets of checks and IDs to the teller.)

- Select a site for your group home in a neighborhood and in a house you'd be comfortable living in!

Dignity of Risk

Dignity of Risk means giving people chances to take the risks that go along with ordinary life, which are necessary for personal growth and development. *Dignity of Risk* is very different from the idea of "protecting" persons with mental retardation by placing them in large institutions or not letting them do the things other people do. *Dignity of Risk* is a principle that must be applied with care and support, based on each person's needs, interests and abilities. As staff in a community program, it will be your responsibility to help the individual develop --*informed* decision-making skills and to provide opportunities and supports - that allow individuals to take certain risks and make their own decisions.

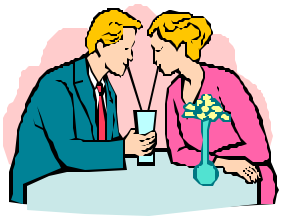
What's Your Role?

You could support the principle of *dignity of risk* by the following activities:

- Support an individual's desire to get a job at a local restaurant, grocery store, or day care center.

- Teach an individual to ride the city bus.

- Assist a person in planning a special date.



- Demonstrate--in a caring way--to a concerned parent that his adult child really can walk to the corner store independently *and* safely for a soda.

Community Presence and Participation

All people with mental retardation and other developmental disabilities belong in the community - in the *same* schools, neighborhoods, stores, and jobs where other people spend their time. John O'Brien, another advocate for people with disabilities, has described *Community Presence* as the experience of sharing the ordinary places that define community life. Without focused effort, people with severe handicaps will be *separated* from everyday settings by segregated facilities, activities, and schedules. Taking people out to ordinary places is the first step, but unless you make the effort, it is possible for the people you support to be present but not actively involved. As program staff, you must take steps to help each individual get involved in activities he wants to do. *Partial Participation* is better than sitting on the sidelines watching others. and means changing parts of a task or materials used to perform a task to allow an individual with disabilities to participate to the fullest extent that is *individually* possible. Your role may include breaking a task into manageable steps that the person can complete. An example of partial participation in making the breakfast might be pushing the handle down on the toaster or holding the glass while someone else pours the juice.

Both persons with disabilities and their peers without disabilities are more enriched by the challenge and opportunities of living, working and playing side-by-side. The principle of *Community Presence and Participation* should guide the selection of sites for homes, the placement into jobs, the development of Consumer Service Plans, the program operation and staff scheduling.

What's Your Role?

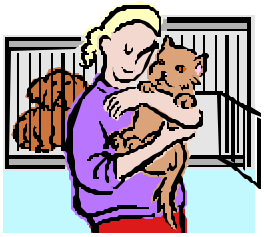
You can help an individual experience *full participation* in the community by:

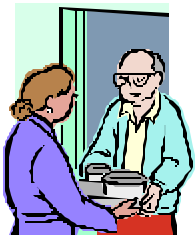
- Convincing your minister or rabbi that adults with mental retardation should attend regular church or temple services and adult classes, not "special classes" for the disabled.

- Find out what a person likes to do and make arrangements for him to participate with your support.

- Avoid taking people out in large groups because this is not how most people participate in the community.

- Assist an individual in becoming a volunteer at a local museum, the SPCA, or other community agency, such as Meals on Wheels or the AIDS Ministry.





- Help an individual get a membership to the YMCA where he or she can participate in regular classes for swimming, aerobics, or weight training.

Nonrestrictive Program Alternatives

When individuals with mental retardation live and work in places which show respect for their rights as human beings, they have a better chance of expressing themselves, reaching their goals, and making choices. "*Nonrestrictive programming*" means supporting people in natural settings and with families and friends by providing flexible, supports that work well for that person. People with mental retardation, should live in

comfortable homes in safe neighborhoods, not in “homelike facilities” in a business district or isolated from other people. They should have the option of working a regular job or as part of a small group of people with disabilities (sometimes called a crew or an enclave).

What’s Your Role?

As a staff person, you can provide *nonrestrictive program alternatives* by:

- Developing a creative way to support an individual in a part-time job despite his “reputation” as a difficult person.

- Allowing an individual the opportunity to assist in meal preparation for himself and his three roommates rather than doing it yourself because it’s faster.

- Being open to the idea that an individual who has shared a dormitory with eleven other people for fifteen years in a state facility may be a very *different* person after he moves to a house in the community with his own bedroom and the opportunity for more choices.

Natural Supports

A concept which is closely tied to nonrestrictive programming is the use of *natural supports* available within community settings. It is the responsibility of staff to find and set up flexible ways of providing services to that specific person in community settings that make use of the supports which are naturally available--family, friends, co-workers, neighbors. Rather than replacing these people with paid staff, creative strategies must be found to support and maintain these relationships. This might include teaching the individual specific skills (such as how to use the city bus), changing staff schedules or patterns (such as going to a church or synagogue close to the individual’s original home), or changing the person’s surroundings (such as supporting an individual in moving to live with a non-disabled family friend).

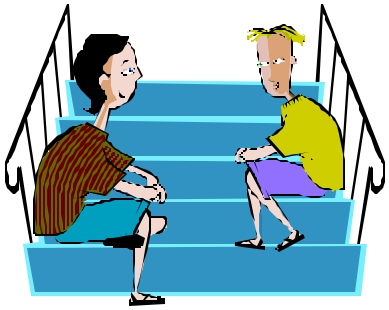
Training is most effective when provided to individuals in regular community settings (such as a grocery store, laundromat, city bus, etc.), in part because people with mental retardation may have trouble performing skills they learned in one setting in a different setting. Training in the real setting also makes the most of natural cues, such as a line of

people ready to check out at the grocery store or a row of spinning dryers. These cues can help strengthen and maintain a new skill. Any routine services that an individual needs should be arranged through the same sources non-disabled persons use (such as the family doctor, dentist, barber).

What's Your Role?

You can encourage the use of *natural supports* by:

- Role-playing and demonstrating conversational skills to assist an individual in getting acquainted with new co-workers.



- Finding a volunteer to accompany a person on a specific activity in which they are both interested, considering also that the individual may have an interest he or she has never had a chance to put into action, such as going to baseball games, hiking, listening to gospel music, taking a cooking class, walking around the neighborhood, taking a drive in the country.

- After noticing the positive bond between an individual and her sister, ask the sister to be involved in and help think of ideas for encouraging them to participate in a new activity together.

Personal Choice

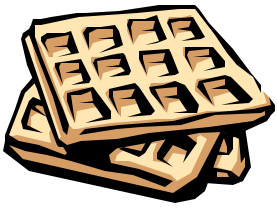
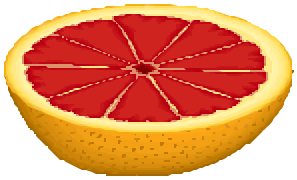
As John O'Brien has noted, "*Personal choice* defines and expresses individual identity. Choice is the experience of growing autonomy in both small, everyday matters, like what to eat or wear, and larger, life defining matters, such as who to live with and what sort of work to do."

An important goal of all service providers should be to provide individuals with opportunities to make both small, everyday choices in the here-and-now as well as bigger, important decisions for the future. This goal must drive the Individual Service Plans that are developed, the way programs operate, the staffing patterns (that is, what staff do and when they do it) and especially, the daily actions of the direct support staff. The choices that are offered should be based on the individual's abilities, needs, and interests.

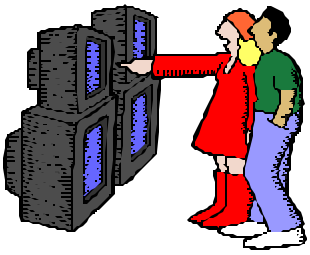
Because a person with severe disabilities may not have experience with making or communicating her choices, others might mistakenly think that she doesn't have a preference or an opinion. Sometimes others worry about the choices the individual might make. It is the responsibility of the program and the staff to provide the person with opportunities to experience making personal choices and with the tools to express her choice.

What's Your Role?

- You ask the person if he would like toast, cereal, or yogurt and fruit for breakfast instead of telling him, "It's Thursday so we're having cereal."


- You help a young woman select affordable but personal furnishings for her bedroom by taking her to shop at several stores in her price range. Talk to her about her likes and dislikes as well as the practical realities of her budget.



- You develop a visual display of volunteer activities to show the possible choices to individuals in your day support program and explain in concrete terms what activities they would be involved with each choice.

- You write down the daily, weekly, and occasional decisions that a person you support makes and then write down the decisions that are made for the person by others. Consider how and what you can do to increase the individual's opportunities and independence in making some of these decisions.

Respect

Adults with mental retardation, just like the rest of us, are thought of favorably when they are in a position to *contribute* to the community. Lack of exposure to persons with disabilities and mistaken ideas which follow, often restrict the opportunities people with disabilities' have to take on roles that are valued in the community. People with disabilities, when given individual assistance, can achieve the *respect* of others by getting the chance to perform useful and meaningful activities.

There is a general tendency to underestimate people with disabilities. Non-disabled persons, even professionals in human services, often focus on the *limitations* rather than the *talents* and *abilities* of people with disabilities. Low expectations can limit people's opportunities to try new things and interfere with their achievements.

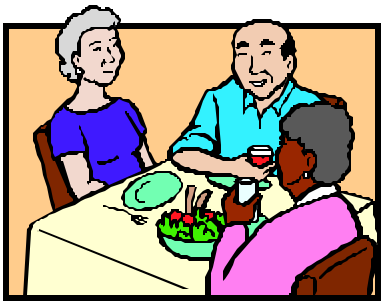
Respect requires seeing the individual as a person first. The disability is only one aspect of his life. It is important to remember that people with disabilities want and need the same things others do - love, security, the satisfaction of personal accomplishment, the opportunity to exercise some control over one's days, environment, and experience, to laugh, and to communicate with others. The way a person experiences these things is different for each, but the desire to have them is the same for everyone.

What's Your Role?

- When supporting a person who is blind, announce your presence, inform the person prior to touching her if necessary, and don't rearrange her belongings without telling her.

- Don't talk *about* the individuals you support in their presence or talk to another staff member or person in the community as if they weren't present.

- If you are staff in a group home, you should join the people you support for meals by sitting with them, and eating the same food from the same dishes they routinely use.



- Don't watch TV, read the newspaper or call your friends while on duty. It's not your home, it's the individual's *home!* It's *your* workplace.

- Every six months, honestly ask yourself, would you like to live in this home or work in this day program?

- Assist the individuals you support to help out in community endeavors. Help them to join neighborhood and civic groups, to be volunteers with other people around town, to vote and to contribute to regular community living.

Individual Rights

People with mental retardation and other disabilities have the same *human rights* as non-disabled people. Like you, they are entitled to enjoy the right to privacy, to marry, to free

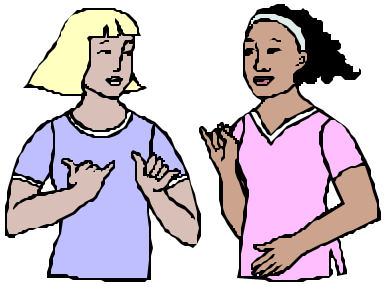
speech, to live in neighborhoods, to vote. Some people with disabilities may have had a few of their legal rights limited through the appointment of a guardian or another legal process. Due to a lack of understanding about people with mental retardation, it is not unusual for an individual to have had certain limitations placed on him such as managing his own money, voting for his governor, even picking out his own clothes--things which he is perfectly capable of handling with individual supports.

As an employee of a community agency providing services to people with mental retardation, you should be aware of these basic human rights, as well as any specific human rights policies followed by your agency. Ask your supervisor to give you a copy and explain your agency's policy to you.

What's Your Role?

- You should carefully read the human rights policy of the agency for which you work. List any questions and discuss them with your supervisor.

- At least once a year, sit down with the people you support one at a time and explain their rights to them in a way that is meaningful to each person--sign language, simple spoken language, or even using pictures to illustrate each right.



- You speak up when you feel other staff are routinely violating a person's right to privacy or other rights.

Zero Reject

Zero reject is the concept that all people with developmental disabilities belong in the community. No matter how severe an individual's disability or challenging her behavior may be, it is possible to develop flexible, individualized supports to help meet her needs. It is the *responsibility* of the program and staff to devise plans to meet an individual's needs and to help her gain or keep skills or change her behaviors.

Community programs used to have very strict entrance requirements, as well as high expectations for allowing people to continue to stay in their program. People who failed to adapt or to meet these criteria went unserved or lost their place in the program. Our understanding of the varied ways in which people with disabilities communicate has grown,

and we now know about the lasting negative affects of living in an institution for a long time. At the same time, the profession has become aware that many of our early methods, especially behavior management, didn't really work and even "dehumanized" people with mental retardation. As we begin to truly recognize the people we support as individuals, our ability to do a good job of teaching and supporting them in community settings grows. Individuals with severe disabilities, who were not considered for the first wave of deinstitutionalization, are now living productive and fulfilling lives in the community.

Zero reject recognizes that it is the responsibility of the community provider agency to develop the supports a person needs to succeed in the community, rather than expect the person to change before she can get those services.

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What's Your Role?

- The day program in which you work is admitting a young woman with a history of yelling and sometimes, hurting others. Additional staff have been hired, and training has been provided in "positive behavioral supports." You commit mentally to working with your team in supporting this individual instead of complaining, "She doesn't belong here."

- You work in a supported living program that is screening individuals for placement. Following a long bout with the flu, one individual has lost many of the self-help skills he once had. Other provider agency staff feel he'll be motivated to learn to care for himself again based on their history with him. You feel it's worth the effort to assist in this and recommend he be admitted.

- The members of your team adjust your work schedules to offer more staff support to a person who has been acting more aggressively following the loss of a parent.

Section II: INTRODUCTION TO MENTAL RETARDATION

Here's the Label, but...

In this section, we will discuss the definition of mental retardation and some of the causes. While this information is important to better understanding the individuals you will support and will help you in your work, it is just as important to understand the myths and misunderstandings which have created barriers for these individuals. Therefore, we will also discuss some of those myths and misconceptions that can get in the way of people living regular lives in the community, and how you can become a *roadblock remover* for the individuals you support.

The Definition of Mental Retardation

People with mental retardation are like people without mental retardation, experiencing the same needs, desires, and dreams. According to the 1992 revised definition developed by the American Association on Mental Retardation, three characteristics must be present to meet the definition of mental retardation:

1. Significantly subaverage general intellectual functioning - an IQ score of approximately 70 to 75 or below based on individually administered intelligence tests.
2. Significant limitations in adaptive skills in two or more of the following areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure and work.
3. Appears before age 18

Historically, levels of mental retardation have been defined based on IQ score: mild mental retardation = IQ of 51-70; moderate mental retardation = IQ of 36-50; severe mental retardation = IQ of 21-35; profound mental retardation = IQ of 20 or less. Because these levels have been used for many years, you will likely see them in the records of people you support. Because they represent only ranges of IQ scores and tell little about the many different kinds of abilities and interests of individuals, these levels provide little useful information in supporting persons with mental retardation.

The 1992 AAMR definition of mental retardation does away with the idea of levels based mainly on IQ and test scores and looks instead at the types and levels of support the individual needs. The definition emphasizes how a person gets along in the world,

recognizing that mental retardation is not a disease or mental illness. Rather, it is a condition which means that the individual needs help (supports) to be successful in the important areas of life, such as living away from one's family, getting around in the community, working, and going to school. The AAMR definition recognizes that, a person's functioning (ability to do things) may improve over time or with supports from others.

Mental retardation is a severe and long-term disability, meaning it results in significant impairments and continues throughout the person's life. Individuals with mental retardation may require lifelong services and supports to live successfully in the community. However, the types and levels of supports required are usually very different from person to person and may even change over time for a single individual.

Causes of Mental Retardation

There are about 250 known causes of mental retardation. Many of the causes are genetic (from the genes of the parents), as in the case of Down Syndrome or Fragile X. Some are environmental causes, as in the case of brain injury resulting from accident or physical abuse or a severe illness, such as spinal meningitis. Mental retardation may also result from long-term social deprivation or poor nutrition.

Myths and Misconceptions

1. <u>All people with mental retardation are alike.</u> Through the years, people with mental retardation have been placed in group settings partly because people think that it's cheaper and easier, and partly because people don't fully understand the disability. The individuals in a given group may have nothing in common other than mental retardation. Their personalities, likes and dislikes, needs and goals vary as much as any other group of people who might be chosen at random. Having mental retardation may mean needing supports to reach a goal that a person without mental retardation might reach by himself. However, the presence of mental retardation does not change the fact that the individual has his own (self-determined) goals. Each person with mental retardation may require some supports, just as we all do in different areas of our life. However, the levels and types of supports appropriate for one person may not be right for another person.

2. <u>People with mental retardation are ill.</u> Mental retardation is <u>not</u> an illness. You can't catch it. It's not something to be cured. An individual with mental retardation may or may not also have a medical condition, physical disability, or mental illness, just as anyone else.

3. <u>People with mental retardation need specialized services to meet all their needs.</u> A person with mental retardation can buy groceries at the same store as a person without mental retardation. The person with mental retardation may or may not need some help with the shopping. A person with mental retardation, who has a medical condition, can

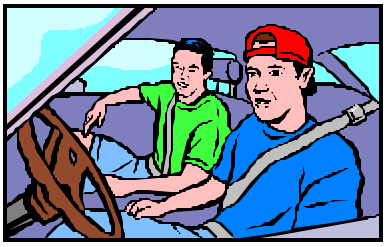
be treated by the same doctor as a person without mental retardation who has the same condition. The person with mental retardation may need some help telling the doctor how she feels, understanding the diagnosis, or taking prescribed medication.

Your Role -- What Can You Do?

1. Be a "*roadblock remover*" -- refuse to look at the label before the person. Get to know each person you support as an individual. Be a friend.

2. If an individual tells you -- by words or behavior -- that she wants to do something, focus your energy on how the person could achieve that goal. A person with mental retardation may need a different route to achieve a goal than someone without the disability. Be creative and help find the route.

3. If you hear someone say something like, "John says he wants to drive a car but he could never do that because he is retarded," start talking about possible ways John could come as close as possible to that goal. If John has never had the chance to see what driving might feel like, suggest that the person (or you) go with John to the mall to drive in a driving simulator at the arcade. Take each person's goals seriously.



4. Try to figure out what a person really wants when he tells you about a goal. If John is saying he wants to drive a car, explore what the idea of driving may mean to John -- freedom, independence, being on one's own, being an adult. Maybe you can think of other things he can do that would also make him feel that way, such as taking a walk in his neighborhood by himself or going to a movie with a friend but no staff.

5. If you find yourself thinking "people with mental retardation can't" thoughts, share these with your co-workers and ask for their suggestions for breaking out of that mind set.

6. Ignore a person's history. A person's history may provide valuable information but should never be used to limit opportunities. The field of mental retardation services is full of stories of people with a "bad history" who have achieved great successes because the people supporting them didn't pigeonhole them based on their history. Wouldn't that be something if you are able to help someone you support to achieve greatness?

7. Model for others. If you treat individuals you support as equals, people in the community will be less likely to treat them as inferiors. When you are in a store with an individual, try to make your support as invisible as possible. Ideally, anyone looking at you will have no reason to see anything other than two friends out shopping together.

Section III: NUTS AND BOLTS OF THE MENTAL RETARDATION WAIVER

The Mental Retardation Community Waiver

The Mental Retardation Community Waiver (MR Waiver) in Virginia provides a way to pay for certain long-term services in communities instead of in institutions. In order to allow this, Virginia applied to the Centers for Medicare and Medicaid Services (CMS) for a waiver of specific federal Medicaid requirements. Since Virginia's application was first approved in 1991, the waiver has provided funding to allow many individuals who would have required institutional services to receive a variety of needed services and supports in the community.

Virginia's MR Waiver is built upon the idea of individualized supports. Services are developed and funded based on a person-centered approach, which allows each individual to have different types and levels of supports based on each individual's goals, choices and needs. People can get either agency services where the provider hires the staff to work with the person or consumer-directed services where the individual (or her family) employs the staff person. They can even get different combinations of both agency-directed or consumer-directed services. The following types of services are available through the MR Community Waiver:

- residential support,
- day support,
- personal assistance,
- respite,
- companion
- consumer-directed personal assistance, respite and companion services
- assistive technology,
- environmental modifications,
- therapeutic consultation in the areas of psychology, behavior, speech, occupational therapy, physical therapy, recreation therapy and rehabilitation engineering,
- personal emergency response systems (PERS),
- crisis stabilization,
- skilled nursing,
- prevocational, and
- supported employment.

In order to be eligible for services funded through the MR Waiver, a person must have mental retardation, or if under six years old, he or she must be at developmental risk. Developmental risk means the child is likely to have mental retardation or another disability, such as autism or cerebral palsy, but she's still too young for us to know yet. Once the child turns six, if she does not have mental retardation, she may need to get services from a different Waiver called the Developmental Disability Waiver. The person must also meet financial eligibility criteria for receiving Medicaid and show the need for Waiver services by meeting specific level of care criteria. Eligible individuals for whom a

slot is available must be allowed to choose whether they want to participate in the Waiver program, what services they will receive, and who the service provider(s) will be. There are a limited number of slots for MR Waiver services, so not everyone who is eligible gets to start services right away.

Each person who is enrolled in an MR Waiver slot is assigned a case manager by the Community Services Board (sometimes called a Behavioral Health Authority) that serves the area in which the individual lives. The case manager works with the individual to develop a Consumer Service Plan (CSP). The CSP addresses the person's strengths, goals, and support needs in important life areas such as residential, education, vocational/work, and recreation/leisure. The case manager is responsible for linking the individual with service providers, coordinating and monitoring the person's services. All Waiver services must be pre-authorized, which means that the case manager must review service plans and request authorization from the Office of Mental Retardation Services for services to be provided at the levels determined to be appropriate for the individual.

SERVICE PLANNING

All MR Waiver services must be delivered according to a written Individual Service Plan (ISP). The ISP has to include an assessment of the person's strengths and needs in relevant areas. Based on assessment information and the individual's desires, long-term goals and short-term objectives are developed. Strategies must be identified for achieving the goals and objectives, and the ISP must be reviewed on a regular basis (usually once every three months). Documentation (written information) is required to show that services are delivered as outlined in the ISP and to provide ongoing evaluation of the appropriateness of the services. Following is a description of each component of the service planning process and documentation requirements.

Assessment

Each service provider is required to learn about the individual's strengths, interests and support needs using approved assessment tools. Formal assessment tools usually contain checklist information regarding the person's skills and support needs in specific service areas. Assessments should be *functional*. That means that information is gathered through a variety of means in order to determine the individual's current abilities in day-to-day community life skills. The best way to learn about a person's strengths, interests and needs is to spend time with her in many different settings, seeing what she can and cannot do, what she likes and doesn't like and by talking to her and others who know her well. The individual's desires are important in identifying strengths and needs. For example, there's no reason to train an individual for years and years how to tie his shoes if he can wear shoes with Velcro and manage them independently. When completing assessments and presenting what you've learned about the individual, it's also more valuable to discuss what the individual *can do* rather than what he *can't do*. The emphasis in planning should be placed on identifying an individual's strengths and interests and building upon them.

Service Planning Team

ISPs are developed by a service planning team with the individual as the central team member. Other members of the team include family members and/or friends of the individual, the case manager, and service providers. The team must meet at least once a year to develop the ISP with the individual. These meetings should be informal, with all team members helping the individual feel comfortable expressing his desires and worries about services and supports. Team members present what they've learned about he individual and make recommendations related to the individual's goals, objectives and services to be provided in the upcoming year. Service plans are developed based on team agreement.

Individual Service Plans

In addition to addressing the individual's needs/desires, ISPs must be written to follow various regulatory and funding agency guidelines. Goals, objectives, strategies, and reviews must be written in a way that follows these guidelines.

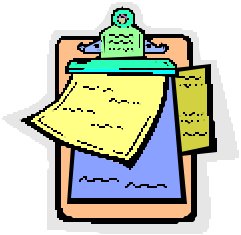
- Long-range goals address the person's desires and other team members' recommendations for personal achievements in 3 – 5 years time.
- Short-term objectives provide steps for working toward the individual's long- range goals. They are usually things the individual can accomplish in a year or less.
- Strategies give staff directions for providing the needed supports (training, assistance) toward meeting objectives.
- Quarterly Reviews: Plans must be reviewed at least quarterly to evaluate whether the individual is satisfied with services and if any changes should be made to reflect changing needs and desires of the individual.

Documentation

Each provider must maintain documentation which shows that services were delivered as outlined in the ISP. Additionally, each provider must have documentation which shows that the plan is being reviewed on a regular basis and that changes are made according to progress and/or the individual's changing needs. Formats and styles for this documentation vary from agency to agency. Specific requirements for the agency where you work will be explained to you by your supervisor.

Your Role -- What Can You Do?

1. Keep accurate documentation. Never "fudge" on required documentation. If you don't understand how to document something, ask your supervisor.



2. Be sure to sign and date all entries in staff notes, logs, etc.

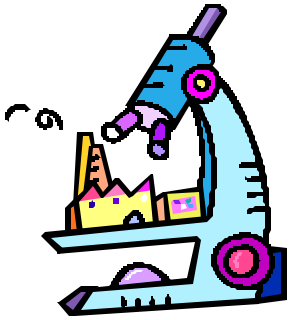
3. Learn to write objectively. Write down what you see, hear, or otherwise observe. Do not include your conclusions or opinions in documentation that is intended to be factual. If you have an idea or a hunch about something, such as why he might be behaving a certain way, make sure you write it as your opinion.

4. Know what's in the ISPs of individuals with whom you work. You are responsible for providing services as outlined in the plan. In addition, when you know what both you and the individual are supposed to be doing, your documentation will reflect this knowledge.

5. If you are unsure or question why a piece of documentation is needed, ask your supervisor to explain. You will be more likely to complete better documentation if you understand the reason for the requirement.

6. As you get to know an individual, share your ideas for changes that might make the ISP better match the person's strengths, interests and support needs.

7. Remember that all documentation is subject to review by licensing and funding agencies and, in some cases, could be subpoenaed for an appeal hearing or other legal action. Provide accurate, clear, detailed information. **Never** use white-out or erase ink. Mark through errors and sign and date any changes to the record.



8. Record information regarding personal likes and dislikes as well as other input from the individual receiving services in appropriate places in his record.

Section IV: COMMUNICATION

Introduction

Communication is of vital importance to all human beings. Communication is defined as the process by which information is exchanged between individuals through a shared system of symbols, language, signs, or behavior. Everyone has the need to communicate, to express choice, to convey pleasure or displeasure, to be heard and seen as a person. It is something that almost every individual is able to do in some way, no matter what the physical, sensory, or mental disability. However, it is usually more of a challenge for individuals with mental retardation to communicate successfully with others and they may experience additional difficulty if they have a hearing or visual impairment. For example, an individual who has severe mental retardation and is also legally blind will have faced many challenges in acquiring language and communication skills--both due to his disabilities and to the attitudes of others. When an individual cannot talk, and especially if he also has mental retardation, people may not bother to *talk to* the person. They may assume the person will not understand what they say.

We all learn language as infants and children through interacting with other people and exploring the world around us. People with mental retardation and other developmental disabilities often have fewer chances to interact and explore. This directly affects their development of language and other communication skills. Many people with sensory impairments (such as visual or hearing impairments or autism) in addition to mental or physical challenges are unable to communicate through speech or sign language. These individuals may understand what people communicate to them and have the desire to respond appropriately. However, they may have trouble *expressing* themselves to others due to their mental or physical challenges. An individual, for example, with cerebral palsy may actually be quite intelligent, but be physically unable to speak clearly due to the physical challenges of cerebral palsy. People with these difficulties may use alternative methods to communicate. They may use gestures, vocal sounds, eye contact, body movements, or facial expressions to get their message across. These alternate methods of communication are called “non-symbolic.”

Non-symbolic interactions require the listener to (1) understand that the individual is trying to get across a message, (2) understand the message, and (3) respond back to the individual. Unsuccessful communication occurs when the non-disabled person doesn’t recognize or respond to the way the person with disabilities communicates.

Since communication involves at least two people, it is important for staff to pay attention to improving the *interactive process* between themselves and the individuals they support. Individuals who communicate in *non-symbolic* ways (not using language or signs) need means to express their likes and dislikes, make choices, ask for things, and show displeasure or unhappiness. The usual way such communication occurs is through the

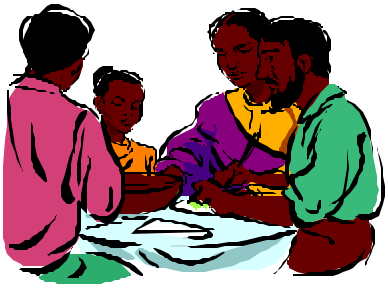
individual's movements and behaviors. The role of behaviors in communication will be reviewed later in this section.

What Can You Do?

1. Pay close attention to any gestures, facial expressions, vocalizations, and movements used by the people you support. Talk to your co-workers and compare notes. Are the same words, sounds, movements used when the person seems pleased? Does she use the same gesture or movement close to mealtimes and something different when there's lots of noise in the house?

2. Talk to your team members about the chances of getting the help of a speech therapist who has experience in both symbolic and non-symbolic communication.

3. Talk to the individual's parents, siblings, and friends. If they've known and lived with the person for years, chances are they understand his communicative efforts quite well.



Communicating with Individuals

No matter how the individual communicates, there are a few basic rules that should be followed whenever you are interacting with a person who has mental retardation:

1. Don't shout!

Some people with mental retardation are hearing impaired, but most aren't. Speak in a normal tone of voice.

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2. ***Talk directly to the person.***
   Don't talk *about* the individual when he's in the room. Don't talk to a family member or coworker when seeking information about the individual's preferences, needs, or concerns unless it's to add to what you've learned directly from the individual. Make eye contact, and make sure you have the individual's attention.

3. ***Communicate with the person according to his/her age.***
   Don't use baby talk or a childlike voice when speaking to adults. Talk or communicate about adult topics. If communicating with a child, focus on age appropriate topics.

4. ***Be flexible and patient.***
   If you normally talk very rapidly, slow down a little. Don't repeat yourself without allowing the person some time to respond. Some people, especially individuals with autism, take much longer to process what you just said. Be patient. Rephrase something – "try another way" of communicating information if you don't feel the person understands you.

5. ***Don't order - ask!***
   You are employed to assist the individuals you support, not the other way around! **Ask** them to perform a task, **invite** them to participate in an activity--treat them with respect, regardless of age or ability. **Do not** talk or act like a parent with the individuals you support – you are not their parents; you are a peer. **Do** share information about yourself in an appropriate way -- as you would with other coworkers or acquaintances. Maintain a respectful, but professional relationship.

Like yourself, you will find that persons with mental retardation and other developmental disabilities respond more positively when treated with respect and consideration. Often an individual's *receptive* language (ability to understand what's said to him) may exceed his *expressive* language (ability to communicate verbally with others). Sometimes it's the other way around. Take your time to communicate, rephrase if necessary, and use a positive and age-appropriate tone of voice.

Communicating with Family Members

As staff in a program for persons with mental retardation, you will interact with the parents and other family members. They deserve the same respect as the individuals you're supporting. Unless an individual has specifically requested that parents or family members not be involved in his life, it is usual to invite family members to individual planning meetings, program celebrations, and other significant events in the individual's life. Parents and other family members are usually important, valued members of the

individual's life. They are also usually very knowledgeable about the individual's likes and dislikes, communication styles, health needs, and history.

Agree to Disagree

As staff, you will play a very different role in an individual's life than his parents. Parents naturally protect their children, and the parents of children with mental retardation are particularly prone to this. From an early age, they must advocate for services for their child, occasionally having to battle "the system." Like all parents, they don't wish to see their children hurt and may have had to shield their children from the unwitting cruelty or ignorance of others. Their family life, their marriage, their other children have all been affected by the demands and, hopefully, the joys of caring for a child with disabilities. They may have cared for their family member for thirty to forty years before she enters the program where you work. They deserve a voice in the individual's continued care.

As professionals, your goal is to assist the individual to be as independent as possible and to have opportunities to participate in the community. Parents may be fearful that this is too stressful for the individual. They may assume *correctly* that you don't know their family member well and then may incorrectly assume you are *overestimating* his capabilities. Listen to their point of view! Your primary responsibility is to assist in the individual's growth and ability to control and participate in the environment. Respect the family's opinions but don't underestimate what people can accomplish. Accept that you may sometimes disagree with family members and it may become emotional. However, if staff maintain a respectful approach and listen to the ideas offered by family members, much can be learned and more can be accomplished over time.

What's Your Role?

1. Listen! You may learn something that will help you in your work with the individual.

2. Respect the family members' opinions, experiences, concerns - but don't let it overshadow your respect for the individual and the possibilities for his life.

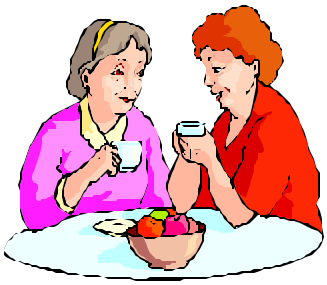
The Effect of Your Choice of Language

Language has an extremely powerful influence over ideas and attitudes. Your choice of words in speaking to and about the people you support is very important to how they perceive themselves and how others see them. Many members of the public have had very little contact with persons with mental retardation. What you say, as someone who supports people with disabilities daily, will most certainly affect the attitudes of others.

Earlier in this workbook, we discussed the importance of treating individuals with mental retardation and other developmental disabilities in a *respectful* way. The importance of seeing the *person first* – apart from the disability – was emphasized. It is more appropriate to say "individuals with mental retardation" than "those MRs." The latter statement lessens the individuals. It emphasizes disability over humanity. The phrases "those MRs" or "autistic people" or even "MR people" reduces the individuals to their handicaps and sets them apart from others. It emphasizes "differentness" rather than sameness. The effect on someone who has never met a person with a disability is to create more distance and discomfort. Recognizing *common* interests, experiences, or needs –*similarities to others* -- creates connections. The phrase "a person with mental retardation" downplays the disability. It says, "He is a person first." It encourages a more approachable image in the mind of someone who may already have fears or mistaken ideas about persons with disabilities.

What Can You Do?

1. Be mindful of using *respectful* language when you speak *to and about* the people you support.



2. Write and say "persons with . . . (disability)" instead of "those MRs," "the deaf," "the blind," etc. Don't mention the disability at all if it's not necessary.

3. Model age appropriate and positive communication at all times.

4. Gently redirect doctors, store personnel, restaurant workers, and others who communicate with you to speak instead to the individual who's being examined, making a purchase, or ordering a meal. If the person is nonverbal, and your assistance is needed to aid in communication, allow her to retain as much control and participate in

the interaction as possible. For example, if the person's receptive language is excellent, you may say, "Please speak directly to her. She will understand you."

The Role of Behaviors in Communication

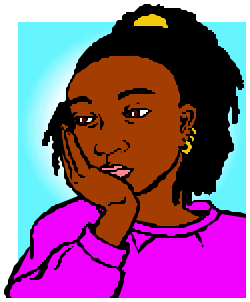
It is important to understand that behaviors, particularly undesirable behaviors (for example hitting, spitting, yelling,) may actually be an individual's attempt to communicate. The inability to make themselves understood is a major cause of frustration and challenging behavior in some individuals with disabilities. Knowing what you want and being unable to express it to others in a meaningful manner is an endless battle for people with limited or poor expressive skills.

It is your responsibility as staff to identify and develop an appropriate means to help the individuals you support express themselves. Just knowing what upsets an individual is not enough. Planning to avoid such situations, as well as assisting people in learning how to deal with life stresses and with learning *appropriate ways* to express themselves is an important part of your job. Later in your training, you will be exposed to different strategies for assisting people in communicating effectively.

It is important to recognize the impact a person's background may have on his communication style. We know that persons with disabilities who have been institutionalized often develop behaviors which are harmful to others or even themselves as a means of attracting attention or getting out of an unpleasant situation. Hitting, spitting, and biting require staff attention or can get someone out of an activity he doesn't want to do; sitting quietly and rocking back and forth in front of the television set usually does not. People who use negative behaviors to communicate will need time and your guidance to develop *alternative (new and positive) behaviors* for communicating their needs or wants. You will learn more about strategies for providing positive behavioral supports in a later section of this workbook and training.

What Can You Do?

1. *Think about the purpose* an individual's behavior may serve. Is she trying to tell you she's frustrated, in pain, bored? Observe and compare notes with your coworkers.



2. *Remember* that a person (particularly someone new to your program) may have learned that *negative* behaviors attract staff attention. Try to consciously reward *positive behaviors* with your time and attention.

3. Be a detective. Sometimes what may look like the individual is just wanting your attention is really his attempt to communicate that he just wants to be left alone. Assume first that he's trying to tell you something, not that he's "being bad."

4. *Respect* that meaningful communication is something all individuals need in order to express themselves and have some control over their environments.

5. *Think about* how you'd feel if you were unable to speak or write and had to develop another means of communication.

Section V: POSITIVE BEHAVIORAL SUPPORT

Introduction

This section provides introductory information about positive behavioral supports by discussing some principles and practices which have been helpful in supporting many people with disabilities to become participating members of the community. More training about positive behavioral support practices may be obtained from your employer or DMHMRSAS staff.

Communicating Through Behavior

Individuals with mental retardation often have communication difficulties (such as being unable to talk or understand spoken language) that get in the way of expressing their needs and feelings in usual ways. This may lead to expressing those needs through behavior that appears unusual or disturbing. Historically, those individuals whose behavior is difficult to manage have been considered in need of institutionalization until they learn behaviors that "show" that they are "ready" for life in the community. However, we have learned that teaching positive behavior in the individual's community home and work settings is a better way to help individuals with mental retardation to change their behavior. Additionally, problem behaviors of many institutionalized people disappear once they participate in the community.

In order to be successful with behavioral supports, staff must treat individuals with dignity and respect. Support staff must view behavior as a way for individuals to control and direct their own lives. If the desire for personal choice and control is not respected, it may result in an individual adopting negative behaviors to gain some control.

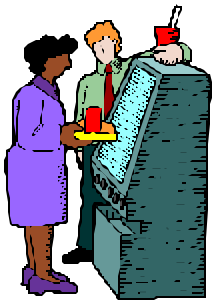
> *For example, the person who is never asked what she wants for breakfast may start to throw her oatmeal across the kitchen every morning.*

In addition, behavioral interventions should be developed with the whole individual in mind, not just the problem behavior. We must look at the behavior within the framework of the person's life. People who have few opportunities to participate in meaningful activities they enjoy with people they like are more likely to display negative behaviors out of boredom or unhappiness.

> *For example, the staff's idea of a community outing is to load up the group home van with all 5 residents and go to McDonald's every Friday night. Bob resists getting on the van and has begun taking off his seatbelt and hitting whoever is sitting next to him.*

In this case, helping the person to find and participate in enjoyable activities with people he likes may go a long way toward removing the reason for the negative behavior.

It is learned that Bob hates going places in large groups, and he also doesn't like burgers. A companion is found to take Bob, one-on-one, to some local diners and cafeterias on Friday evenings.



Additionally, people (with or without mental retardation) generally do not behave at their best when they are feeling pain or discomfort. A person who is hungry, thirsty, or tired may act in a negative way to express these feelings. Some problem behaviors result from side effects of medications. Others result from unhappiness, which may be due to missing family or friends, the absence of a favorite staff member, dislike of work, or an argument with a housemate or coworker. Reasons for behavior are as unique as individuals. If we are to support people in successfully changing problem behaviors, we must first do our best to know these individuals and what is happening in their lives.

Functional Assessment of Behavior

When a behavior interferes with an individual's ability to live or work successfully in the community, the first step in addressing the behavior of concern is to try to figure out the purpose of the behavior. This is done by first defining the problem behavior, in ways that can be seen and measured.

In our example of Bob, staff might be making notes such as:
"At first Bob refused to get on the van for a trip to McDonalds."
"Once on the van he began hitting his neighbor."
"At the intersection, Bob took off his seatbelt."
"Bob ate little of his dinner tonight. Ate most of his salad and pie, but only took one

bite of his hamburger."

Information is then gathered which may tell us why the person is acting in that way. This information is provided through formal data collection tools, such as documentation of the times and frequency of the behavior, and informal tools such as interviews of staff, family, and/or other care providers who support the person. Information such as when a behavior occurs, what is going on around the person at the time, who else is present, and what happens immediately following the behavior can be critical in determining the purpose or function of the behavior. What happens immediately after the behavior, is probably *(but not always!)* what the individual was wanting.

Staff working with Bob may also note that the van stops to deal with Bob's behavior of hitting and unbuckling, delaying the trip, or that the "consequence" for his behavior is that he doesn't get to go on the trip the next week (just what he wanted all along!).

Intervention

Changing the Environment or Routines

Once the function of the behavior is determined, the most important step involves making changes in the individual's surroundings or routine and starting new supports to eliminate or prevent the need for the behavior. For example:

- *If a person is behaving aggressively due to a toothache, assisting the person with getting treatment from a dentist should help to stop the need for the behavior.*
- *An hour of relaxation after work may help someone do better during the evening hours.*
- *Individual time with staff may reduce the need to scream for attention.*

Sometimes all it takes to help an individual behave in less challenging ways is to *change the setting* (reduce the noise, limit the number of people, go someplace she likes), *change our behaviors* (ask rather than demand, talk about the day's schedule, speak quietly) or *change our expectations* of him (give him more time to eat, let him choose the day's fun activity, not require him to participate).

*For Bob, the **setting** was changed (limiting the number of big group van trips in which he's expected to participate and taking him to restaurants that don't just feature burgers as their main offering). Also, the staff's **expectations** of Bob were changed (he can choose different restaurants and go with a companion instead of "the big group").*

Teaching a New Behavior

While things usually get better by making the above kinds of changes, this might not totally address the behavior of concern. When this is the case, the next step is identifying and teaching a new or "replacement" behavior that would give the person another way to get his need met.

> *For example, if a person is hitting people as a way of communicating that he wants to stop participating in an activity, an effective replacement behavior might involve teaching the individual to show that he wants to stop by handing a card to support staff.*

If this gives the individual the same results, as quickly and consistently as the problem behavior does – *that is the demand from staff to participate in the activity is removed* – then the individual may learn that he does not need to continue hitting others in order to communicate that message.

In teaching a replacement behavior, it is important that the new behavior **works** every time for the person.

> *In the example of the person communicating that he wants a break, handing the card to a staff member must be effective in getting a break, if the person is to learn that this is an efficient replacement behavior.*

It is also important for staff to point out positive consequences, which flow naturally from the new behavior and make it more likely that the person will engage in the behavior again.

> *For example, when a person bathes, she experiences feeling/smelling clean. She may enjoy this feeling and, thus, be more likely to want to bathe.*

In addition to responding consistently to positive behavior, support staff must be ready to respond effectively when problem behaviors occur. If a behavior will not harm the person or others, it is often best to ignore the problem behavior, while continuing to respond consistently to the desired behavior that the individual is learning.

> *Staff working with the person resisting bathing would ignore her high pitched squeals at bath time and remind her how good she'll feel and smell after her bath. The behavior plan might also call for staff to offer her choice of bubble bath or scented soap.*

When behavior places the individual or others in danger, ensuring safety and minimizing risk become the immediate focus. **Staff should not try to teach desired behaviors during a time when dangerous behavior is occurring.** It's best not to worry about what is learned during these times or that the individual might be "getting his way." It's more important for everyone to be safe and calm (and to learn from these experiences what the individual really wants so that he can be supported in a way that helps him to be happy with his life). When the individual becomes calm, the focus can again turn to teaching the better way to behave.

Much behavioral support is provided through unplanned or social teaching. Individuals with mental retardation, like all people, learn from watching how others act in a given situation. This is why teaching behavior in the **community settings** where the person lives and works is very effective. The individual must be provided with opportunities to experience different environments – stores, restaurants, banks, ballparks, hair salons – in order to learn to interact with others in those environments. Support staff who go with an individual in community environments must remember that you are a role model not only for the individual to learn how to behave, but also for the people in the community that the individual meets. If you treat the individual respectfully, you will show others how to do so also.

<u>Behavior Support Plans</u>

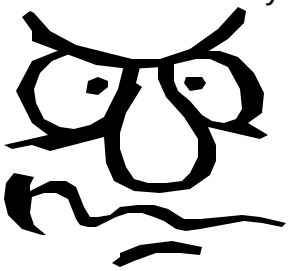
Individual behavioral support plans are often developed for persons who have particularly challenging behaviors. Once the appropriate interventions are identified through the

functional assessment process, a behavior support plan should be developed to teach the individual the desired behavior. A behavior support plan outlines what changes are needed in the environment or the individual's schedule or routines, how staff should support the individual and respond when the behavior occurs, what new behavior the individual can use to get what he needs and wants, and the methods for teaching the person the new, replacement behavior. Behavior support plans are designed to help staff be consistent, that is *to act in the same way*, in supporting the individual.

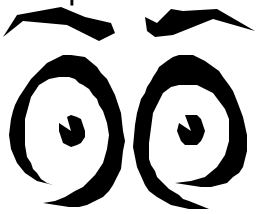
In supporting behavioral change, human rights protections are a primary consideration. The Department of Mental Health, Mental Retardation and Substance Abuse Services has established guidelines to protect the rights of individuals served by providers licensed by the Department. Each such provider is required to have a human rights policy, which has been approved and which provides adequate protections for individuals served by the agency. If you work for a DMHMRSAS-licensed provider, you will receive additional training regarding the human rights policy which applies in the agency where you work. Behavior intervention plans must comply with the human rights regulations and policy. In general, restrictions of an individual's rights, even those done for the purpose of teaching behavior, should be avoided. At the very least, they must be part of a formal behavior support plan.

Your Role - What Can You Do?

1. Be a good role model. It will be difficult for people to look to you to teach them anger management if they see you yell and scream when you get angry.



2. Be a good observer. As a direct service staff member, you will have the most contact with the individual and will generally be the first to notice changes in behavior or behaviors that are interfering with the person's life in the community.

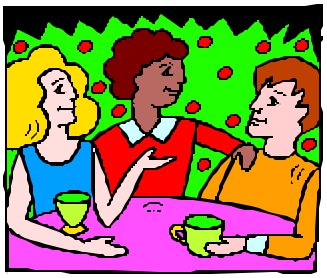


3. Keep good documentation. Your observations are critical in determining the purpose (or function) of a challenging behavior. Record accurate information regarding patterns of behavior: times, places, surrounding events, what happens after he does it.

4. Follow behavior support plans. In order to support people effectively, the same (consistent) teaching strategies must be used by all staff. In addition, behavior plans must comply with human rights guidelines. By carefully following behavior support plans, you help make sure that the person's rights are protected and that the new, replacement behavior is successfully taught.

5. Be a good communicator. If individuals are verbal, listen to what they tell you about their choices with words and behavior. If individuals are non-verbal, pay close attention to what they tell you through behavior. By doing this, you will often be able to assist people in exercising choice and control, which will make it less likely that negative behavior will develop.

6. Be supportive and respectful. The individuals with whom you work have the same desire you have to be accepted in the community. Socially unacceptable behaviors may have been learned for a variety of reasons based on the individual's life history and experiences. When you treat people with respect they are more likely to trust that you are trying to help reach their goals and, thus, you will be a better teacher.



7. Commit to problem-solving. When a person lives in the community, problems may arise due to behaviors that keep the person from fully participating in community life. Put your creativity and energy into helping find solutions that increase the person's ability to become a valued, participating community member.

8. Assist individuals with improving quality of life. Many negative behaviors are due to boredom and unhappiness. Look at people's lives to see if they have opportunities to make friends, participate in activities they like, and take on new challenges. Find ways to help each person increase those opportunities. For example, go with a person to join a club that focuses on the individual's interests.

9. <u>Point out natural reinforcers.</u> Help individuals with whom you work to notice the positive effects of certain behaviors. Walk with a person who has just combed his hair to a mirror and point out how good his hair looks. In time, he may go to the mirror alone and note whether the grooming was successful.

Section VI: HEALTH AND SAFETY

Introduction

A vital part of your role as staff in a community program is to make sure that the individuals with mental retardation whom you support are as healthy and safe as possible. Your responsibilities will depend on the type of program in which you work. For instance, while staff in day support, case management, or in-home services play a vital role in carefully *observing* individuals and in *reporting* any changes in behavior, appearance, or eating habits that may relate to good health, congregate residential staff often have the additional responsibility of arranging for and accompanying individuals to doctor or dental appointments.

In addition to this chapter of the workbook, you may receive First Aid and CPR training to assist you in your work. You may also receive training and be tested in procedures for safe administration of medication. This chapter is not intended to replace that training. In general, your role is to help the individuals access quality health care, assist them in learning or practicing behaviors or skills which maintain good health, and help them become aware and informed regarding their own health concerns.

Maintaining Good Health Through Good Nutrition

People with mental retardation have the same needs for good nutrition and maintenance of proper weight as non-disabled persons. Since mental retardation and other developmental disabilities can be associated with other medical conditions, such as epilepsy, allergies, diabetes, and heart problems, you may support people who are required to follow a special diet for health reasons. Depending on the needs of individuals, your role may include planning nutritious and well-balanced meals or assisting the individual in doing this, overseeing meal preparation, and noting food consumption.

Important Point: As staff in a community program for persons with mental retardation, resist the temptation to reward or coax good behavior with food. Individuals with mental retardation experience the same problems with excess weight as the rest of us. Many of them have never had the opportunity to experience a regular exercise program. When you wish to reward someone for positive behaviors, offer a meaningful, *non-edible* reward, such as:

- ✓ A fifteen minute walk around the neighborhood,
- ✓ A telephone call to a relative or friend,
- ✓ A short shopping trip,
- ✓ A visit to the library.

What's Your Role?

1. Read the medical and social history records for all individuals you support.
    - *Who's* on a special diet?

- *Who* has food or other allergies? If so, what are they?

2. Monitor an individual's food intake during meals, but do so in an age-appropriate, respectful manner.

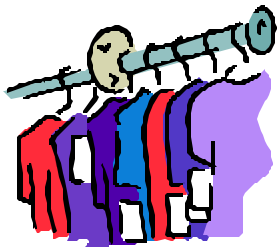
    - *For example, if an individual has difficulty with overeating, serving food family style may create too much temptation and lead to conflict. An alternative would be to prepare everyone's plate in the kitchen, possibly serving smaller helpings initially to allow for the satisfaction of "seconds."*

3. See the Food Guide Pyramid on page 44 to help you in meal planning.

Personal Hygiene

An individual's maintenance of his or her personal hygiene plays a major role in how others perceive that person. It is important for all of us to wear clean clothing, to keep our hair clean and healthy, and to bathe regularly. For people with mental retardation, it is even more important. Already perceived by others as "different," individuals with mental retardation will be seen as more unappealing if they are wearing dirty clothing or have a sloppy appearance.

It is likely you will work with some people who need prompting or assistance to keep up their personal appearance. Depending on the needs of the individual, your assistance could range from physically bathing to helping someone shop for attractive shirts that are appropriate for his new job.



Maintaining good hygiene, including dental care, is also important for health reasons. Lack of attention to bathing or routine care of teeth and gums can lead to serious medical conditions. You may support people who don't understand this and may not enjoy participating in such activities. It will be your responsibility to develop strategies for encouraging individuals to participate in necessary bathing, shampooing, and the other personal hygiene activities.

Important Point: You should expect the personal hygiene of the individual you support to be kept at a level equal to your own, your child, your spouse. It is no less important!

What's Your Role?

1. You provide residential supports to a young man who drools due to a severe cleft palate. To assist him with maintaining a positive personal appearance, you take him to purchase several sets of men's handkerchiefs and teach him how to wipe his chin, if needed, with a simple verbal prompt.

2. You help a person find a dentist who accepts Medicaid or offers reduced rates for low income patients.

3. One of the individuals in your day support program is having toileting accidents. You alert the case manager and residential staff that the team needs to try to identify the cause, such as medical problems, behavioral communication, depression, etc., and come up with a solution in the meantime, such as extra change of clothing maintained at the day program or possible short-term use of Depends.

Regular Medical and Dental Care

Scheduling regular doctor and dental checkups is *usually* the responsibility of residential staff or family if a person lives at home. However, all staff who work with individuals with disabilities should look for changes in appearance or behavior which may be symptoms of illness. It has been shown that challenging behaviors are frequently the only means of communicating physical or mental pain for some individuals with mental retardation. Since some persons with mental retardation are unable to tell you how they feel or what a change in health may mean, staff must be responsible for monitoring this regularly.

The following lists areas where changes *may* indicate signs of illness or a change in health status:

A. Changes in Daily Patterns
   1. Eating/ digestion
   2. Sleeping

3. Injury
4. Medication - changes and reactions

B. Changes in Appearances
1. Weight gain or loss
2. Condition of skin or hair
3. Eyes: appearance or sensitivity
4. Swelling/redness
5. Hygiene deterioration (such as body odor, untidy clothing, bad breath)

C. Changes in Bodily Functions
1. Breathing
2. Balance/dizziness
3. Vital signs (such as pulse and blood pressure)
4. Bowel movements
5. Mobility - use of hands, arms, and legs
6. Senses - seeing, hearing, touch, taste, smell

D. Changes in Behavior/Demeanor
1. Obvious change in mood (such as depression, crying, agitated)
2. Combative/argumentative
3. Withdrawn
4. Anxious, restless
5. Obvious change for that individual (previously energetic person appears listless or a typically quiet individual talks nonstop).

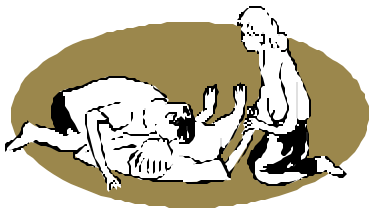
What Can You Do?
If you notice any of the changes listed above, you should:

1. Note it in the staff communication log so others can be aware and observant. Documenting incidents of these changes may be key to diagnosing a problem if one exists.

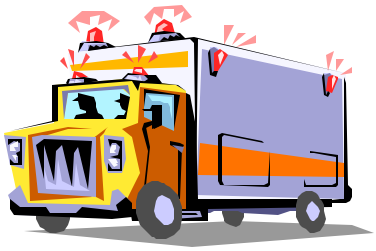
2. If you're new to a program and note changes in an individual, speak to your supervisor or a co-worker to get a perspective on the person's history.

3. When in doubt, and if symptoms persist, call a doctor!

Emergency Care
You will most likely receive or have received training in First Aid and Cardiopulmonary Resuscitation (CPR) prior to supporting individuals alone. This will enable you to react appropriately and possibly to save someone's life while medical care is on the way.



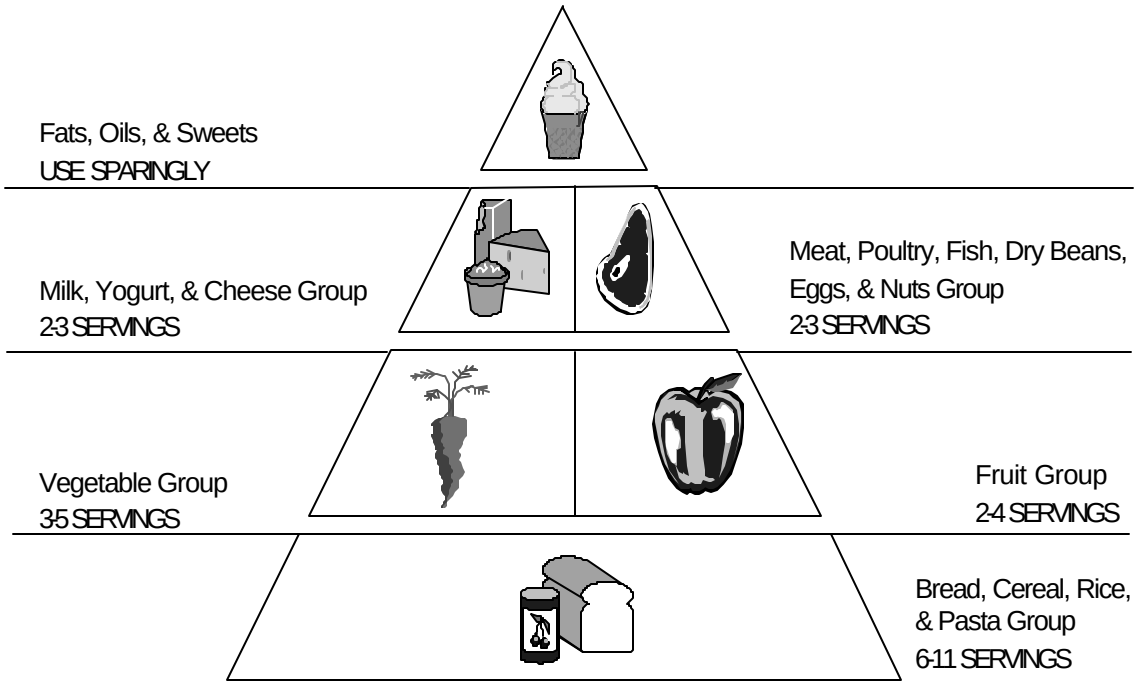
It goes without saying that any condition which would be considered an emergency if it happened to a member of your family is also an emergency if it occurs to a person with mental retardation. Call 911 at the *first* sign of a medical emergency!



Important Point: Since many individuals with mental retardation have other medical concerns, such as epilepsy, diabetes, food or drug allergies, it is *very* important that staff become aware of any *individual signs or symptoms* of medical distress. People who have epileptic seizures often signal an oncoming seizure through an involuntary facial expression or other behavior. Get to know the people you support. It may mean the difference between life and death.

FOOD GUIDE PYRAMIID

The U.S. Department of Agriculture has published the perfect maintenance plan for you in the form of the Food Guide Pyramid, which we have reproduced for you here.



(Source: U.S. Department of Agriculture/U.S. Department of Health and Human Services

There is also a *children's adaptation* of the original Food Guide Pyramid: the "Food Guide Pyramid for Young Children." This features images of single-serving foods commonly eaten by children such as a chicken drumstick, a lollipop, waffles and green beans.

This may be obtained from the USDA Center for Nutrition Policy and Promotion http://www.usda.gov/cnpp/.

You may also write/call for the Food Guide Pyramid, Home and Garden Bulletin Number 252 at:

USDA Center for Nutrition Policy and Promotion
1120 20th Street, NW, Suite 200N
Washington, DC 20036
Tel: 202-418-2312

References and Suggested Readings

O'Brien, John. (1987). "A Guide to Personal Future's Planning." The Activities Catalog: A Community Programming Guide for Youth and Adults with Severe Disabilities. Baltimore MD: Paul H. Brookes Publishing Co.

Vanderheiden, Gregg, C. & Yoder, David E. (1986). Augmentative Communication: An Introduction. American Speech-Language-Hearing Association.

Wolfensberger, Wolf. (1972). The Principle of Normalization in Human Services. Toronto, Canada: National Institute on Mental Retardation.

MR STAFF 0RIENTATION WORKBOOK EVALUATION

Date: _____ Name: _____
(optional)

Name of employing agency:_____

Program type (day support, residential, etc.): _____
Please rate the Orientation Workbook by circling the appropriate number.

	Disagree	Unsure	Somewhat Agree	Agree
1. The information is helpful.	1	2	3	4
2. The information is organized.	1	2	3	4
3. The information is clear.	1	2	3	4
4. The information includes most of what you needed to know in the first month of work.	1	2	3	4
5. Your job responsibilities became clearer after this training.	1	2	3	4

6. The training you received was done by: (Check all that apply)

___ Small group (2–6 people) ___ One-to-one supervision ___ Self-study (no help)

7. What did you like best about the training?

8. What didn't you like about the training?

9. What are your suggestions for improving the workbook or exam?

10. What are your suggestions on how to use the workbook to orient staff?

Mail or fax to:
Dawn Traver
Community Resource Unit
ESH, Bldg. 10, PO Box 8791
Williamsburg, VA, 23187-8791
Fax # - (757) 253-5440

Test: The Values that Support Life in the Community

Name: _____ Date: _____

Please circle the correct answers for the following multiple choice and true/false questions:

1. The principle of "normalization" suggests that people with mental retardation:

   A) should be treated according to how they scored on their IQ tests.

   B) should be assisted in leading lives which are as normal for their culture and as appropriate for their age as possible.

   C) should not be pushed to behave like other adults because it's too stressful.

   D) should be protected from the difficulties of normal, everyday life.

2. All of the following are examples of applying the principle of "normalization" ***except:***

   A) The group home van has no signs or markings to indicate its use.

   B) You introduce a person you support to your spouse by saying, "John, this is my friend, Teresa."

   C) You help a person select an attractive lunch box that does not feature a Disney character.

   D) You are concerned that one of the five individuals you are taking to an amusement park may get lost in the crowd, so you buy baseball hats which are printed with "Brook Road Group Home" for each person to wear.

3. Persons with mental retardation:

   A) are all very similar.

   B) always need assistance with personal hygiene.

   C) are all very different individuals.

   D) should be treated like children rather than adults.

4. The concept “dignity of risk” means that the risks that are part of ordinary life:

   A) are too dangerous for people with mental retardation.

   B) can lead to personal growth, development and fulfillment for individuals who are developmentally disabled.

   C) are so great that people with mental retardation must live in large institutions to have safer, risk free lives.

   D) are allowable if the person has signed a release of liability.

5. One of the most important staff responsibilities in following the concept of “dignity of risk” is:

   A) getting a release of information signed by the individual’s parent.

   B) allowing the people you support to do anything they choose to do.

   C) providing the people you support with meaningful information about the possible consequences of their actions so they can make informed choices.

   D) telling the people you support what you think is the safest way for them to behave.

6. An example of the principle of “community presence and participation” is:

   A) putting signs in front of the group home so the public will understand that individuals with disabilities have a right to live in the community.

   B) special camps for children and adults with disabilities which create a separate, safe community.

   C) taking the people in your day support program to see Santa Claus at the mall.

   D) helping a person you support become a volunteer at a local hospital.

7. Based on the principle of “community presence and participation,” people with disabilities are more enriched when they:

   A) participate primarily in activities with other people with disabilities because they’re the only people who really understand them.

B) attend special classes which are taught at a slower pace.

C) have the chance to experience routine community activities and to interact with people who are non-disabled.

D) live and work with the same individuals with disabilities.

8. "Nonrestrictive program alternatives" include:

A) giving a person with a disability the choice of attending the sheltered workshop, looking for a job in the community, or working in a small group of people with disabilities.

B) telling a person he must live in the group home for a minimum of two years before getting his own apartment.

C) giving everyone in the day program Diet Pepsi for lunch, even though there are other options available.

D) putting someone in whatever program has a vacancy regardless of his interests or needs.

9. An example of using "natural supports" is:

A) teaching someone who needs transportation to a weekday job to ride the bus at 10:00 a.m. on Saturday instead of rush hour on a weekday because there are fewer passengers.

B) helping the people you support to join the neighborhood association where they live, so they can meet some of their neighbors.

C) leaving the people you support in the van while you run in the convenience store to buy drinks for everyone.

D) teaching someone to iron without plugging in the iron.

10. People with mental retardation cannot indicate choice unless they are verbal so it is essential that speech therapy be available to all people with mental retardation. **(True / False)**

11. It is important to offer individuals both immediate choices, such as what to eat for lunch and long-term choices, such as where and with whom to live. **(True / False)**

12. It is more respectful to allow persons with mental retardation to safely experience the activities of daily community life than to protect them by only offering "special activities" with others who also have disabilities. **(True / False)**

13. Among the reasons adults with mental retardation are often not given the respect they deserve is:

    A) a tendency to see the disability rather than the person first.

    B) a lack of experience with or exposure to persons who have disabilities.

    C) a tendency to view adults with mental retardation as childlike.

    D) all of the above.

14. Talking about the people you support in their presence is okay if you're certain they don't understand what you're saying. **(True / False)**

15. People with mental retardation have the same rights to privacy, due process, speech and freedom of religion as non-disabled persons; however, they don't have the right to vote or the right to marry. **(True / False)**

16. As an employee of a Community Services Board or private agency serving persons with mental retardation, you will be responsible for respecting the human rights of the people you support and following related agency human rights policies. **(True / False)**

17. "Zero Reject" means that:

    A) all individuals with mental retardation can be served in the community with the appropriate supports.

    B) a community program must admit anyone who applies.

    C) programs cannot develop waiting lists for services.

18. Individuals with extremely severe disabilities:

    A) can only be served safely in highly specialized programs.

    B) require flexible, individualized supports.

    C) are safest and happiest in state facilities.

Test: Introduction to Mental Retardation

Name: _____ Date: _____

1. The definition of mental retardation includes:

   A) significantly subaverage intellectual functioning.

   B) an inability to communicate verbally.

   C) onset before age 12

   D) all of the above.

2. In order to provide a person the right services, the most important thing to know is:

   A) the person's level of mental retardation.

   B) what services the person has been receiving.

   C) what services a psychologist recommends.

   D) what the person's goals are.

3. Mental retardation may be caused by:

   A) genetic or chromosomal factors.

   B) trauma such as accidents or physical abuse.

   C) social deprivation.

   D) all of the above

4. Which of the following is true of mental retardation?

   A) A cure has not yet been found, although research is getting closer.

   B) The best way to provide services to people with mental retardation is by grouping them according to level of mental retardation.

   C) Supports may be required throughout the lifetime of an individual with mental retardation.

D) Only doctors who specialize in treating individuals with mental retardation are capable of providing good medical treatment to people with mental retardation.

5. Staff can assist people with mental retardation in breaking out of the label by talking to them as equals. **(True / False)**

6. If a person who is non-verbal frequently points to pictures of airplanes and smiles, some things a “roadblock removing” staff person might do include arranging for a plane ride or helping the individual visit an air show. **(True / False)**

7. A person with mental retardation cannot drive a car. **(True / False)**

8. The best way to support a person with mental retardation is to provide opportunities based on the information about past successes and failures. **(True / False)**

9. A person who suffers brain injury as a result of a car accident at age 25 would receive a diagnosis of mental retardation. **(True / False)**

10. A person with severe mental retardation always requires much more intensive services than a person with moderate mental retardation. **(True / False)**

Test: Nuts & Bolts of the Mental Retardation Community Waiver

Name: _____ Date: _____

1. The Mental Retardation Community Waiver (MR Waiver) pays for:

   A) services to persons with all types of disabilities.

   B) services provided to people with mental retardation in communities as an alternative to institutions.

   C) services only for children with mental retardation.

   D) necessary medical services.

2. Choice of service providers for MR Waiver services is made by:

   A) the individual receiving services.

   B) the psychologist who evaluated the person.

   C) the person's doctor.

   D) agreement of the above individuals.

3. Assessment should:

   A) be conducted by service providers who work with the person.

   B) be functional.

   C) identify the individual's strengths, interests and support needs.

   D) all of the above.

4. Individual Service Plans must be written:

   A) by doctors.

   B) to meet Licensing and Medicaid guidelines.

   C) weekly.

D) by Medicaid.

5. The central member of the service planning team is:

A) the individual receiving services, unless he/she is non-verbal.

B) the individual receiving services.

C) the individual's mother.

D) the case manager.

6. Documentation should:

A) be accurate.

B) be completed according to agency requirements.

C) relate to what's in the individual's ISP.

D) all of the above.

7. Writing objectively means you should write in the records what you observe, not your opinions. **(True / False)**

8. Long-range goals will always take 5 years to reach. **(True / False)**

9. In the ISP, strategies guide the way training and assistance are provided to a person. **(True / False)**

10. Only program supervisors and case managers need to know what's in an individual's ISP. **(True / False)**

11. Providers must maintain documentation showing that services are delivered according to the individual's ISP. **(True / False)**

12. ISPs must be reviewed regularly to determine whether the person's needs require changes to the ISP. **(True / False)**

Test: Communication

Name: _____ Date: _____

Please circle the correct answers for the following multiple choice and true/false questions:

1. The only way people can truly communicate is by talking to each other. **(True / False)**

2. Some people with mental retardation *may* have trouble communicating because:

   A) they had limited opportunities for language development as infants.

   B) in addition to mental retardation, they have a sensory impairment, such as blindness or deafness or a physical disability, such as cerebral palsy.

   C) people don't take the time to communicate *with* them.

   D) all of the above.

3. It is possible for an individual with mental retardation to have a greater understanding of what is said to him (receptive language) than he is able to express clearly to others. **(True / False)**

4. People may communicate through:

   A) spoken or written language.

   B) behaviors.

   C) signs or gestures.

   D) A and C only

   E) A, B, and C

5. Use of gestures, vocal sounds, eye contact, body movements or facial expressions are examples of _____ communication.

   A) non-symbolic

B) symbolic

C) ineffective

6. As staff, your role as listener includes:

A) convincing the individual you understand even if you don't to avoid hurting his feelings.

B) making every effort to accurately interpret the message received.

C) teaching the individuals you support to communicate through language since this is most convenient.

D) making the individual you support use signs that everyone else uses.

7. If you are unable to understand an individual's speech, her family probably *cannot* provide you with any additional information. **(True / False)**

8. The best way to communicate with people with mental retardation is to talk very loudly and very slowly. **(True / False)**

9. Using baby talk or a childlike voice when talking to adults with mental retardation is inappropriate. **(True / False)**

10. Examples of phrases which devalue the people we support:

A) "those MR's"

B) "he's a Down's"

C) "deaf and dumb"

D) all of the above

11. When working with individuals with developmental disabilities, it is most effective to use the following *tone of voice*:

A) parental

B) pleading

C) respectful

D) threatening

12. Families and staff usually agree on what's best for the individual and experience little conflict. **(True / False)**

13. Identify the behavior(s) below which a person may use to communicate information:

A) shouting
B) crying
C) biting (self or others)
D) scratching
E) smiling
F) head banging
G) urinating
H) signing
I) laughing
J) all of the above

14. It is possible to teach a person to substitute positive behaviors (such as handing someone an instruction card) for challenging behaviors (such as biting, kicking, hitting) as a means of communication. **(True / False)**

Test: Positive Behavioral Support

Name: _____ Date: _____

1. Individuals with mental retardation who exhibit challenging behaviors:

   A) may be trying to exercise control over their lives.

   B) may be bored or unhappy.

   C) may be communicating in a non-customary way.

   D) all of the above.

2. Providing positive behavioral support requires:

   A) treating individuals with dignity and respect.

   B) only saying positive statements so you don't hurt anybody's feelings.

   C) enforcing strict rules and control so individuals know what to expect.

   D) all of the above.

3. Functional assessment of behavior means:

   A) taking a person with challenging behavior to a doctor in order for the doctor to prescribe medication to make the behavior stop

   B) looking at behavior as communication and trying to figure out why the person is behaving in a challenging way.

   C) treating all individuals with mental retardation and all challenging behaviors the same way.

   D) all of the above.

4. Guidelines which must be followed by DMHMRSAS-licensed programs about the development of behavior plans are found in:

   A) the local newspaper.

   B) the Mental Retardation Journal.

C) Human Rights policy.

D) federal law.

5. In determining the purpose of a behavior, it is important to:

A) gather information about the frequency and intensity of the behavior.

B) document accurate observations.

C) gather information regarding the surrounding environment when the behavior occurs.

D) all of the above.

6. If a person exhibits challenging behavior, she should live in an institution until the behavior is eliminated **(True / False)**

7. A person may communicate through behavior. **(True / False)**

8. One way to make it less likely that a person will exhibit negative behaviors is to improve the person's quality of life. **(True / False)**

9. Restrictions on individual rights must comply with human rights principles. **(True / False)**

10. Staff observations of behavioral changes and patterns are not of much importance in developing effective behavioral supports. **(True / False)**

11. Most people, except for those with mental retardation, have a desire to control their day-to-day lives. **(True / False)**

Test: Health and Safety

Name: _____ Date: _____

1. As a staff in a community program for individuals with mental retardation, one of your responsibilities is to support the health and safety of the clients with whom you work. **(True / False)**

2. Using candy or a tasty snack as a reward for desired behavior is recommended in working with individuals with mental retardation. **(True / False)**

3. People with mental retardation *always* have related medical problems. **(True / False)**

4. You can get information about a person's medical concerns and general health by:

   A) reading the individual's medical and social history.

   B) observing the individual in different situations and over time.

   C) reading the staff log or talking with your co-workers.

   D) all of the above

5. If an individual refuses to wash his hair, then he is making a choice, and there is little staff can do. **(True / False)**

6. Changes in appearance, behavior, or manner can be symptoms of illness **(True / False)**

7. Observing individuals' changes in appearance or behavior is only the responsibility of *residential* staff and not the responsibility of day support or other program staff. **(True / False)**

8. It is essential that people with mental retardation:

   A) have regular medical and dental care.

   B) only see a doctor when they ask for one.

   C) go to a pediatric dentist.

D) are able to bathe themselves.

9. The Food Guide Pyramid for adults recommends:

A) 4 – 5 daily servings of meat or poultry.

B) 3 – 5 daily servings of vegetables.

C) 4 servings a day from the milk, yogurt and cheese group.

D) 3 daily servings of bread, cereal or pasta.

10. Healthy nutrition is as important for people with mental retardation as it is for anyone else. **(True / False)**

Administered by: _____ Date: _____

Name: _____ Score: _____

MR Staff Orientation Workbook Exam
ANSWER SHEET

Please circle the letter which corresponds to the most appropriate answer.

Section 1: Values

1. A B C D
2. A B C D
3. A B C D
4. A B C D
5. A B C D
6. A B C D
7. A B C D
8. A B C D
9. A B C D
10. T or F
11. T or F
12. T or F
13. A B C D
14. T or F
15. T or F
16. T or F
17. A B C
18. A B C

Section 2: Introduction to Mental Retardation

1. A B C D
2. A B C D
3. A B C D
4. A B C D
5. T or F
6. T or F
7. T or F
8. T or F
9. T or F
10. T or F

Section 3: Nuts and Bolts of the MR Waiver

1. A B C D
2. A B C D
3. A B C D
4. A B C D
5. A B C D
6. A B C D
7. T or F
8. T or F
9. T or F
10. T or F
11. T or F
12. T or F

Section 4: Communication

1. T or F
2. A B C D
3. T or F
4. A B C D E
5. A B C D
6. A B C D
7. T or F
8. T or F
9. T or F
10. A B C D
11. A B C D
12. T or F
13. A B C D E F G H I J
14. T or F

Section 5: Positive Behavioral Support

1. A B C D
2. A B C D
3. A B C D
4. A B C D
5. A B C D
6. T or F
7. T or F
8. T or F
9. T or F
10. T or F
11. T or F

Section 6: Health and Safety

1. T or F
2. T or F
3. T or F
4. A B C D
5. T or F
6. T or F
7. T or F
8. A B C D
9. A B C D
10. T or F

Direct Support Staff Assurance Certificate

I recognize that, as a condition of providing Residential Support and/or Personal Assistance Services under the MR Waiver, the following requirements must be met. I hereby assure that, as a staff person delivering these services, the following events have occurred as described:

1) I have received instruction from my supervisor regarding the contents of the "MR Staff Orientation Workbook."

2) I have taken and passed (with a score of 75% or better) the "MR Staff Orientation Exam."

3) The above events occurred within the first 30 days of my employment as a provider of Residential Support and/or Personal Assistance Services under the MR Waiver or on the date listed with my signature.

_____ _____
Direct Support Staff Signature Date

_____ _____
Supervisor's/Trainer's Signature Date

_____
Agency Name

_____
Agency Address

Please keep this on file for viewing during a Utilization Review. Keep a copy for your own records.

Supervisor Assurance Certificate

I recognize that, as a condition of providing Residential Support and/or Personal Assistance Services under the MR Waiver, the following requirements must be met. I hereby assure that, as supervisor of these services, the following events have occurred as described:

1) I have viewed the "Supervisor Training video," reviewed the accompanying materials, and read the "MR Staff Orientation Workbook; **or**
received training on utilizing the "MR Staff Orientation Workbook from the following DMHMRSAS-trained individual: _____.

2) I am using the "MR Staff Orientation Workbook" to train all staff who will be providing Residential Support and/or Personal Assistance services within the first 30 days of their employment.

3) The process I am using to impart the contents of the "MR Staff Orientation Workbook" is as follows [keeping in mind the "Do's and Don'ts" in the video]:

_____

_____

_____

4) The process I am using to test employees and document their passing of the exam is as follows:

_____

_____

_____

_____ _____
Supervisor Signature Date

_____
Agency Name

_____
Agency Address

Please keep this on file for viewing during a Utilization Review. Keep a copy for your own records.